

Missouri's Fight Against Arthritis & Related Conditions



A STATE PLAN FOR 2002-2007

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Stories of Arthritis



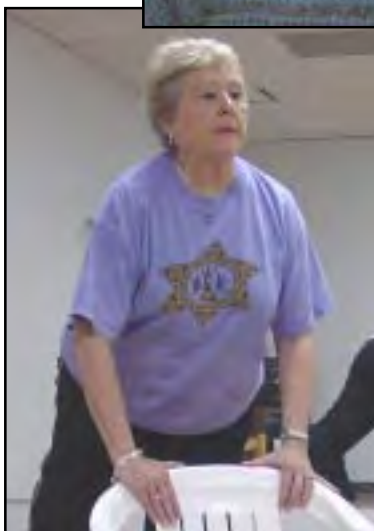
Rosalind French

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Kaitlyn Clark

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Suzanne Pfeffer

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Robert Green

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Stories contributed by
Dianna Borsi O'Brien, Osamu Fujimaru
and Andy Shea.

Forward



The Missouri Arthritis Action Plan for 2002-2007 and the supportive documentation is meant to provide a comprehensive framework to direct the efforts of all partners in a coordinated approach to reduce disability and improve the quality of life of Missourians with arthritis and related conditions. The purpose of the plan is:

- To clearly describe what arthritis and its related disease processes are, and that it affects 1 out of 3 Missourians;
- To describe arthritis disease management interventions taking place in Missouri;
- To identify opportunities for reducing disability and improving the quality of life for Missourians with arthritis;
- To offer information regarding arthritis disease management activities that can be implemented to help control the debilitating disease;
- To call upon Missourians to take action by becoming members of the Missouri Arthritis Alliance and by including arthritis related activities in daily personal, business and community life. By doing so, we hope to reduce the burden of arthritis in Missouri.

Your participation is crucial to the success of this plan. Please join our efforts by initiating the Missouri Arthritis Action Plan in your community. With your commitment to implement the goals, aims and strategies outlined in this plan, the burden of arthritis will be lessened in Missouri.

Chris Kerns, Chair
Missouri Arthritis Advisory Board

Preface

“The 20th century brought remarkable and unprecedented improvements in the lives of the people of the United States. We saw the infant mortality rate plummet and life expectancy increase by 30 years”, said Donna E. Shalala in a message included in the national Healthy People 2010.

Advancements in medical technology and health care have contributed to an increased life span. However, most advances came from prevention efforts. Public health emphasis has been to reduce mortality (death) from disease. While this will remain an effort of public health, the increase in life span now makes it imperative to refocus the emphasis on preserving quality of life, sustaining productivity, and fostering good physical and mental health. Arthritis has been recognized as the leading cause of disability, affecting an estimated 1.5 million (37%) Missouri adults. Arthritis impacts individuals physically, economically, psychologically, and socially. Arthritis efforts in Missouri need to focus on prevention, when possible, and proper medical and self-management, if affected, in order to help preserve quality of life, sustain productivity of its citizens, and to assure physical and mental well being.

In an effort to address the issues surrounding arthritis in Missouri, an alliance has formed that is comprised of numerous partners including not-for-profit organizations, academic institutions, public health agencies, and private organizations. A current member listing can be found in Appendix 1. As members of the alliance, we

are proud to present the *Arthritis Action Plan: Missouri's Fight Against Arthritis and Related Conditions*. This plan is a result of the collaborative efforts of many individuals and agencies that have contributed their time and expertise. This plan serves as a comprehensive framework that includes key strategies and aims. It provides guidance to design, implement, and evaluate arthritis-related activities for three target populations: the general public, people with arthritis and their families, and health care systems. The alliance is committed to coordinating efforts that will produce the most effective, efficient, and comprehensive benefits for these groups.

Sincere gratitude is extended to everyone who has contributed to the development of this plan. Every Missouri citizen, organization, community group, industry, business, and health care system is invited to become a member of the alliance and be involved in the implementation and evaluation of this plan. Together we can look forward to a brighter future where Missourians live healthy, productive and happy lives.

Sincerely,

2002 Members of the
Missouri Arthritis Alliance

Acknowledgements

This plan is a result of collaborative efforts of many individuals and agencies. The Missouri Arthritis and Osteoporosis Program would like to gratefully acknowledge and thank these individuals and committed organizations that generously shared their time and expertise to create this plan. It is only with the continued commitment of the individuals and organizations in the Alliance that the goals, aims, and strategies outlined in the Missouri Arthritis Action Plan will be realized. A special thank you is extended to the following individuals and organizations for helping to create a vision for Missouri's future in arthritis initiatives:

Area Agencies on Aging

Marilee Bomar, RN, MSN, Central Missouri Regional Arthritis Center

Debbie Braby, RHIT, Northwest Missouri Regional Arthritis Center

Crystal Brady, Arthritis Foundation – Central Missouri Branch

Doris Fountain, RNC, CDE, Northeast Missouri Regional Arthritis Center

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Bureau of Chronic Disease Control

Missouri Arthritis & Osteoporosis Program

Executive Summary

Nationally, arthritis and related conditions affect approximately 43 million Americans, or one out of every six people. It is a costly health problem and the leading cause of disability in the United States. Arthritis is one of Missouri's most common chronic health problems affecting more than one in three (37%) residents 18 years or older. Contrary to popular belief that arthritis afflicts only the elderly, it is estimated that 41.5% of adults between the ages of 35 and 64 and 4,000 children under the age of 18 suffer from this disabling condition.

This Action Plan sets out to identify primary, secondary and tertiary prevention mechanisms to address the needs of Missourians with arthritis. The goals identified are: (1) to reduce disability caused by arthritis or chronic joint symptoms; (2) to increase public awareness of arthritis and related conditions as the leading cause of disability, the mechanisms of prevention and management, and available resources; (3) to expand arthritis education, programs and support services throughout the state for people with arthritis and their families, particularly the elderly, women and children, underserved populations who may lack access to healthcare services, and other high-risk populations; (4) to improve quality of health care practices and enable a responsible and accountable health care system for all Missourians with arthritis and related conditions; and (5) to enhance and strengthen surveillance/monitoring of disease prevalence, related risk factors, and the national health objectives (Healthy People 2010).

A comprehensive review of the current and future needs for addressing arthritis and related conditions was completed through planning meetings and workshops. Furthermore, endorsement and support of this plan was established through the same venue. Incorporating public health approaches: health communication and education; community and health systems-based interventions; surveillance, research and evaluation; and partnerships and advocacy; will be integral in guiding all governmental and non-governmental agencies, health systems/providers, voluntary and community organizations, and other partners to enhance current endeavors and become involved in activities that will improve Missourians' lives.

Knowledge and awareness surrounding arthritis and the effective mechanisms for controlling and managing the disease is growing. The diligent efforts of those involved in the prevention and management of arthritis will make significant inroads and positively impact the lives of Missourians affected by this debilitating disease.

This plan provides a framework to guide arthritis efforts, a blueprint for achieving goals. The plan is for use by governmental and non-governmental agencies, health systems, community organizations, and others. This plan is a dynamic document, and only a few suggested activities for each aim have been noted in order to initiate ideas. This plan will unify efforts and initiate action of individuals and organizations involved in arthritis care, research, management, and education.

PART I: Issue

Though there are more than

100 different types of arthritis

and related conditions, for the purpose of this document the word arthritis is used as an umbrella term. Nationally, arthritis affects nearly 43 million Americans, or one out of every six people (adults and children),^{1, 2} making it one of the most common diseases in the United States. Arthritis is a serious, often misunderstood, and costly public health problem. Arthritis is the leading cause of disability in the United States³, and people with arthritis are also more likely to be affected by co-morbidities (other chronic diseases or illnesses). Among all adults with disabilities, 17.5% reported that the main health condition associated with their disability was arthritis or rheumatism, making it the number one cause of disability in the United States.³

Six Most Common Types

Osteoarthritis: The most common type of arthritis affecting the breakdown of the cartilage layer causing the bones to rub together resulting in pain, swelling, and loss of motion of the joint.

Fibromyalgia: A disorder that causes general pain in the muscles and joints (ligaments and tendons).

Rheumatoid Arthritis: An autoimmune disease in which the joint lining becomes inflamed as part of the body's immune system activity.

Gout: A disease that causes sudden, severe periods of pain, tenderness, redness, and inflammation in some joints.

Systemic Lupus Erythematosus: A serious autoimmune disorder that can inflame and damage joints and other connective tissues throughout the body. Also known as Lupus or SLE.

Juvenile Rheumatoid Arthritis: A common form of rheumatoid arthritis in children.

Adults

For the purposes of monitoring the burden of arthritis, the Centers for Disease Control and Prevention (CDC) defines arthritis as those individuals reporting doctor-diagnosed arthritis and/or chronic joint symptoms. According to this definition, an estimated 1.5 million⁴ Missouri adults are living with arthritis and related chronic joint symptoms. Arthritis affects every segment of the population, but most commonly affects older individuals 65-74 years (55%), women (40%), people with low incomes (<\$20K/year) (46%), and people with less than a high school education (51%). More than 25% of those reporting arthritis were **not** doctor-diagnosed, implying that additional effort is needed to increase awareness of the importance of early diagnosis and treatment.

Children and Adolescents

While prevalence of arthritis increases with age, it should be recognized that children are also affected by any of the 100 forms of arthritis. According to Dr. Cassidy at the University of Missouri-Columbia, an estimated 4,000 children have arthritis in Missouri. The impact of arthritis on children can dramatically affect their quality of life, even as they age. Therefore, addressing the needs and promoting proper management of their disease is paramount and can have profound benefits in terms of their productivity, psychosocial benefits and long-term health outcome.

Geographic Distribution

Geographically, the prevalence of arthritis does not substantially vary among Behavioral Risk Factor Surveillance System (BRFSS) districts in Missouri. Yet, when comparing metropolitan to non-metropolitan areas, there appears to be a slightly higher prevalence in non-metropolitan areas (35% and 41%, respectively).⁴

Impact

Arthritis imposes a tremendous economic, psychological and social impact on the individual arthritis patient and their family. People with arthritis are often disabled and unable to work. Of Missourians unable to work, 74% have arthritis. Since adults with arthritis are four times more likely to be unable to work than those without arthritis, this greatly impacts them and their families economically. Approximately 35% of adults with arthritis are also limited in some activity due to a health problem and 40% require aid for personal care. The costs of arthritis, both direct and indirect, can affect one's quality of life. In Missouri, arthritis costs an estimated \$1.3 billion, with \$294 million spent on medical care in 2000. Missouri's costs were derived using the state's proportion of the adult population affected by arthritis and national arthritis cost estimates. Hip and knee osteoarthritis is the leading cause of arthritis disability and the primary reason for high costs associated with expensive joint replacement surgery. Arthritis and related disorders were the 7th leading cause of Missouri hospitalizations in 1995.⁵

Who Is At Risk?

In addition to the elderly, women, and those with low income or education, there are other populations at high risk. Farmers are at increased risk for developing work-related disabilities including arthritis. Over 20% of Missouri's farmers, ranchers and agricultural workers have a disease, disorder or disability that limits their ability to perform some work-related or daily-living tasks.⁶

Individuals who are severely overweight are also more likely to have arthritis resulting in disability.^{7, 8} Among Missouri adults with arthritis, 30% are obese and 39% are physically inactive, compared to 16% and 25% of adults without arthritis.⁴ Obesity has been shown to play a causal role in osteoarthritis of the knee.^{9, 10, 11, 12} These lifestyle factors compound the problem of arthritis, leading to greater pain and disability.

If an individual is overweight or obese, reduction in weight, in some cases, may prevent the onset of osteoarthritis. Other forms of prevention for osteoarthritis can result from preventing injuries, joint trauma and repetitive joint usage caused by sports/athletics or occupational sources.¹⁰ A history of joint trauma is the strongest risk factor for unilateral osteoarthritis at either the knee¹¹ or the hip.¹²

Early diagnosis and appropriate, ongoing arthritis management are known to reduce or improve long-term discomfort and disability and improve emotional health and overall quality of life.

Modifiable Risk Factors

Although some risk factors that put populations at greater risk cannot be changed, such as age, gender and race, there are several modifiable factors. Physical inactivity, overweight/obesity and poor nutritional habits play a significant role in arthritis. Controlling modifiable risk factors can greatly improve mobility, minimize pain and disability, and improve quality of life.

Plan Development

With the burden of arthritis clearly defined, an action plan to address arthritis issues was initiated. The Missouri Arthritis and Osteoporosis Program convened the planning process that involved persons with arthritis, physicians, allied health professionals, researchers, public health officials, business and community interest groups, and state, professional and non-profit agencies. The process included: (1) an in-depth review of 1999 National Arthritis Action Plan and current Missouri arthritis programs and initiatives; (2) input gathered from the Missouri Arthritis Advisory Board, Regional Arthritis Centers and the Arthritis Foundation; (3) a series of regional planning meetings in collaboration with the Regional Arthritis Centers in seven designated regions of the state facilitated inclusion of community partners to review the plan, provide comments and make suggestions; and (4) review and concurrence provided by the Missouri Arthritis Advisory Board, Regional Arthritis Centers, and Arthritis Foundation Chapters. In the planning and development of the arthritis action plan, the Missouri Arthritis Advisory Board identified and prioritized the outcomes to be achieved in 3-5 years, thus impacting the long-term (10-year) goals. The individuals convened as part of the planning process are the foundation of a network of organizations and individuals with arthritis interests and resources that will be the basis of a newly formed Missouri Arthritis Alliance. The Alliance is a communication network of partners that share information about current research, opportunities for partnerships, programs, and plan accomplishments.

Education Is The Key To Coping With Arthritis

Rosalind French was 24 when first diagnosed with rheumatoid arthritis. By the time she was 40, the disease had taken its toll and French was forced to take an early retirement. After 16 years of fighting an illness that forced her to give up regular exercise and retire from her job as a senior medical technologist, surgery to her foot left her confined to a bed. She was practically housebound until a friend convinced her to volunteer at a local chorus.

“That got me going 100 percent. It triggered me to get up and not just vegetate in the house,” said French. “It motivated me.”

Once on her feet, French signed up for an arthritis self-help course and an exercise class through her local regional arthritis center (RAC). Today, some five years later, the northern

St. Louis County, MO, resident is back in the swing of things. French says it’s all due to an arthritis self-help course she took several years ago. There, she learned how to live with arthritis. “Education is key,” said French.

At the classes, French learned several new techniques to live a full life despite having arthritis. For example, mornings are not as difficult as they once were because she now sets her clothing and breakfast items out the night before. French keeps a bar stool in the kitchen so she can sit while preparing food, and to make sweeping easier, she uses a long-handled dust pan.

French has learned how to make things easier, and she has learned not to sweat the small stuff. Today, French continues to volunteer in her community, works at a part-time job and stays physically active. “You just keep on going. You don’t let it get you down,” she said.

***“You just keep on going.
Don’t let arthritis
get you down.”***

- Rosalind French, St. Louis County



**Education is
key to arthritis
management.**



PART II: Opportunity

Lessening The Burden:

Opportunities for Improvement



With proper disease management and management of modifiable risk factors, people with arthritis, osteoporosis and other chronic diseases can achieve improvements in mobility, minimization of pain, and improvement in overall health. Physical activity is just one critical activity that has multiple health benefits: it reduces the risk of developing a number of other chronic health conditions like diabetes, heart disease and possibly osteoarthritis. Physical activity can improve muscle strength, increase endurance and flexibility;¹³ strengthen bones, help reduce and maintain appropriate body weight, reduce hypertension, help control or prevent diabetes, and provide better overall health. Additional strategies are listed below.

While researchers search for an arthritis cure, pain and disability can be reduced. Reducing pain and discomfort, preventing deformities and loss of joint function, and maintaining a productive and active life are major treatment goals. A comprehensive treatment plan and program should include medical management, options to reduce joint stress, physical and occupational therapy, drug therapy, surgical intervention, pain management techniques, self-management techniques, and social and emotional support for the individual and their family. The first step should be visiting a doctor and getting a proper diagnosis. Early diagnosis can allow the individual to intercept the process at an early stage and reduce the potential disability that may result.

Self-management is another important step. Self-management education has been shown to be effective in reducing pain and minimizing disability from arthritis and related conditions.^{14, 15} Management of arthritis and related

conditions can be achieved by following a regimen of regular physical activity that is appropriate for the individual that has arthritis, osteoporosis, or a combination of both. Since being overweight or obese compounds the effects of arthritis, maintaining a healthy body weight by being physically active and having a well balanced diet is another component of self-management. Weight management can reduce the pain and disability and, in some cases, prevent the onset of the disease.¹¹ Missouri has a number of self-management programs that are available to facilitate healthy lifestyle changes.

Using proper joint protection techniques daily is an important arthritis prevention strategy.

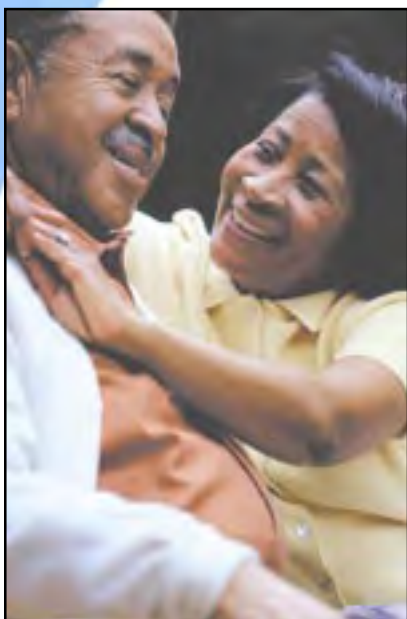
In some cases, the risk of developing arthritis may be reduced by mechanisms of primary prevention like joint protection. Using recommended injury prevention strategies (warm-ups, stretching and appropriate use of equipment) helps to avoid joint injuries and damage to cartilage and ligaments. Taking precautions to avoid repetitive joint use and resulting joint injury can help to prevent arthritis. Raising awareness among youth, in particular athletes, encouraging adoption of healthy ways to be active, and avoiding or reducing trauma or overuse of joints may also help reduce the risk.

Recent breakthroughs in biomedical research have increased the understanding and treatment of arthritis. A number of new medications are available to treat rheumatoid arthritis, osteoarthritis, osteoporosis, and related conditions. Additionally, surgical interventions may be an option when the pain and deterioration of the joint can no longer be managed by other treatment plans.



PART III: Current Programs

Missouri's Arthritis Alliance



The Missouri Arthritis Alliance is made up of existing programs and partners, as well as individuals and organizations, that indicate an interest in helping people with arthritis at the local, regional, and state level. Membership is open to anyone who wants to become active in the fight against arthritis. The Alliance is a communication network of partners that share information about current research partnerships, programs and plan accomplishments.

Missouri arthritis advocates have an excellent history of working together to reduce the burden of arthritis. A list of current partners and individuals (Alliance members) who have indicated they want to be involved in the implementation of this plan is included as Appendix 1. Members of the Alliance correspond through a listserv that is managed by the Missouri Arthritis and Osteoporosis Program. To become a member, please complete the form and follow the instructions found at the back of this publication.

Missouri Arthritis & Osteoporosis Program:

16+ Years of Experience:

www.dbss.state.mo.us/maop

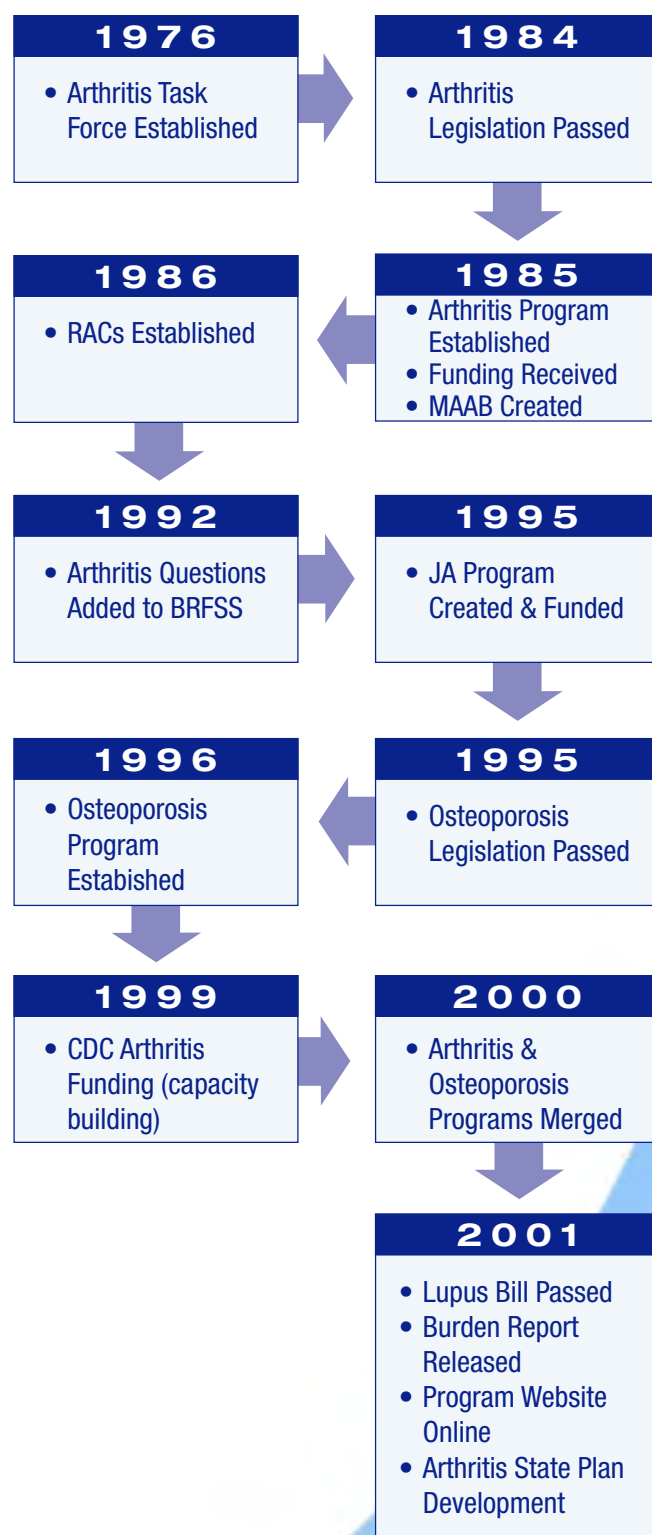
The Bureau of Chronic Disease Control, a part of the Missouri Department of Health and Senior Services (DHSS), Division of Chronic Disease Prevention and Health Promotion (CDPHP), administers the Missouri Arthritis and Osteoporosis Program (MAOP). Appendix 2 provides a schematic of the organizational structure of the program. Missouri has the longest standing state arthritis program in the nation. Figure 1 illustrates the program's history. The Missouri Arthritis Task Force was established in 1976. Early arthritis advocates held hearings across the state and developed a three-volume report for the Governor. The key recommendations included: (1) establishment of a network of Regional Arthritis Centers that support activities in three program areas (education for health professionals, improved patient care and education of patients, their families and the public);

(2) support for the advancement of arthritis research; and (3) support for the training of rheumatologists. Ultimately, passage of legislation in 1984 created a statewide arthritis program within the Department mandating the creation of a state arthritis advisory board and the establishment of Regional Arthritis Centers in seven designated regions of the state. Most recently, the arthritis program joined forces with the osteoporosis program to become the Missouri Arthritis and Osteoporosis Program (MAOP). In 2001, the Missouri 91st General Assembly passed legislation establishing a state lupus program that will be administered by the Department. The MAOP serves a leadership role in the coordination and implementation of arthritis, osteoporosis and lupus prevention and education. The program's mission is to promote optimal health and quality of life for all Missourians affected by arthritis, rheumatic disease and related musculoskeletal conditions. Missouri's program continues to be a leader in establishing a public health approach for arthritis.



In 1985 the Missouri Arthritis Advisory Board (MAAB) was legislatively mandated and established to provide expertise and resources to empower Missourians with arthritis and guide strategic planning for the MAOP program. The MAAB consists of a variety of health care professionals, people with arthritis, community partners, and arthritis advocates. MAAB members address issues of communication, programs, and surveillance through standing committees. The MAAB is an integral part of the MAOP. The Board's executive committee provides guidance and support to the standing committees, MAOP, and the Regional Arthritis Centers.

Figure 1: Program History Schematic





Regional Arthritis Centers

In 1986, after a thorough review process by the Peer Review Committee of the MAAB, eight Regional Arthritis Centers (RACs) were officially designated in seven regions of the state. Currently, there are seven centers. The RACs are located within facilities (hosting institutions) that provide or have access to comprehensive health care for individuals with arthritis or other related rheumatic diseases. Centers are located in St. Louis, Southeast Missouri, Northeast Missouri, Northwest Missouri, Central Missouri, Southwest Missouri, and Kansas City (see Appendix 3). RACs are an integral part of the MAOP because they provide care for people with arthritis through a variety of programs and services such as:

- Self-management programs;
- Physical activity programs;
- Professional education programs;
- Public awareness activities; and
- Individual education.

RACs are funded in part by the MAOP.

Juvenile Arthritis Care Coordination

Begun in 1995, this program is a joint effort of the Missouri RACs and the Missouri DHSS' Bureaus of Special Health Care Needs and Chronic Disease Control. These Bureaus recognize and help with the special needs of families of children with arthritis and other rheumatic conditions. Since 1995, five pediatric rheumatology centers throughout Missouri have been awarded contracts to provide service coordination dedicated to helping families of children with rheumatic disease.

The diagnosis of a rheumatic disease in a child often comes as a surprise to many, including the child and the family. The Juvenile Arthritis Service Coordination Program understands that the family has a need for education about their child's disease and that they may need help educating others about

the diagnosis. The family may encounter several new areas of concern: medical, financial, HMO/Insurance, transportation and scheduling. Families may also want to be connected to support services or to become active in community events where they can meet with other families affected by rheumatic disease.

Juvenile Arthritis Service Coordinators help families secure the services and support they need:

- Identification of children and teenagers with arthritis,
- Referral services,
- Education and medical information,
- Resource library,
- Community education workshops,
- Family advocacy services,
- Family support groups,
- Summer camp information,
- Kids on the Block puppet shows and
- Links to community events.



The Arthritis Foundation is a national, non-profit organization with a history of providing arthritis programs and services to Missouri residents for over 50 years. Currently, there are two chapters in Missouri. The Eastern Missouri Chapter was established in 1949 and the Western Missouri Chapter was founded in 1979. The Arthritis Foundation's overall mission is to improve lives through leadership in the prevention, control, and cure of arthritis and related diseases. In order to achieve this mission, the Missouri Arthritis Foundation chapters provide and/or partner to provide programs for people with arthritis, including public education, professional education, and support for research.

Such partners include, in part, the MAOP, Regional Arthritis Centers, and Universities. The Foundation chapters and the MAOP meet on a regular basis to coordinate, plan, and streamline program implementation, public's awareness about arthritis, and disease reporting. In addition, the Foundation chapters work locally with the Regional Arthritis Centers in the areas of information dissemination, presentations, and training of volunteer leaders.





The Arthritis Foundation chapters offer several education and exercise programs to help people with arthritis or related diseases better control and manage their disease. The programs include: Arthritis Self-Help Course; Fibromyalgia Self-Help Course; People with Arthritis Can Exercise (PACE); Arthritis Foundation/YMCA Aquatics Class; and Arthritis and Fibromyalgia Support Groups. The Chapters work with MAOP and the RACs to implement these programs in communities across the state.

The Missouri chapters also provide public education and information on arthritis through literature, community educational forums, community health fairs, physician referral information, and speakers to community groups.

In addition, the Foundation is an important educational resource for children with arthritis and their families. The Missouri chapters and the American Juvenile Arthritis Organization (part of the Arthritis Foundation) provide education activities throughout the year for children with juvenile arthritis and their families. These activities also provide peer support for kids and parents affected by juvenile arthritis.

Finally, the Missouri chapters have long been supporters of arthritis research. The Arthritis Foundation funds arthritis and arthritis related research to find cures for and to develop better ways to treat the many forms of arthritis. Currently, the Arthritis Foundation funds research projects at universities and medical institutions, and supports fellowships to train and recruit new rheumatologists.

MARRTC Missouri Arthritis Rehabilitation Research and Training Center

The Missouri Arthritis Rehabilitation Research and Training Center (MARRTC) plays a significant role in improving the quality of life for Missourians with arthritis. Funded by the National Institute on Disability and Rehabilitation Research of the U.S. Department of Education, MARRTC is a national leader in the area of arthritis rehabilitation research and training. MARRTC is the only federally funded center dedicated to arthritis rehabilitation and research in the United States.

For more than 15 years, MARRTC has made significant contributions in research on the bio-psychosocial aspects of arthritis, the effects of exercise on arthritis, the association of depression and arthritis, dissemination of information, and other topics. Currently, MARRTC research projects include investigations into the effects of managed care on people with arthritis, vocational rehabilitation for people with arthritis, providing information and technical assistance to farmers with arthritis, and the dissemination of arthritis information.

In 2002, MARRTC co-sponsored the first international conference on arthritis and exercise. MARRTC hosts an award winning website and partners with the MAOP, the RACs and the Missouri chapters of the Arthritis Foundation to disseminate arthritis information, maintain an electronic calendar of activities and events, and maintains web pages for each RAC.

Lupus Foundation of America, Inc.

The Lupus Foundation of America, Inc., is a non-profit organization that currently has two chapters in Missouri. One chapter is in Kansas City and the other is in St. Louis. The Foundation works to improve the quality of the lives of people living with lupus through community awareness and public education, research and patient services and support. The two chapter offices in Missouri work jointly with the RACs and the MAOP in the planning process.



Partnerships

It is imperative, if Missouri is going to reduce it's burden of arthritis, that health agencies, medical societies, academic institutions, nonprofit organizations, health professionals, patients, and volunteers work together to improve the health and quality of life of Missourians affected by this disease.

Partnerships are organizations, providers, and citizens joining together to communicate, cooperate, coordinate, and collaborate to achieve a common goal or outcome within a geographic area. Every partner brings a unique point of view, set of resources, and range of abilities. Partnerships are critical in order to achieve Missouri's vision for people with arthritis. Alliance members have the opportunity to build partnerships among themselves, their communities, existing partnerships, and state and regional entities to implement activities that are appropriate, and that will improve the quality of life, of people with arthritis.

Strong and committed partnerships already exist between the hosting institutions of the RACs, the Arthritis Foundation, the Lupus Foundation of America, Inc., MARRTC, Washington University, and St. Louis University, which have contributed to the success of statewide community arthritis interventions. Individuals from these organizations regularly participate in advisory and planning meetings at the regional or state level. The MAOP has established internal partnerships and coordinates activities with the DHSS' Office on Women's Health, Office on Minority Health, Division of Maternal Child and Family Health, Division of Aging, and other chronic disease programs (cardiovascular disease, diabetes, asthma, obesity, cancer, and tobacco control programs).

Partnerships will continue to build Missouri's infrastructure and ability to provide programs and resources for the target populations. A few examples of community partnerships include:

- Referring patients/clients to nearest self-help course, i.e., arthritis self-help, chronic disease self-help, or fibromyalgia self-help or to the nearest Regional Arthritis Center or Arthritis Foundation Chapter office for information;

- Becoming a trained leader in the arthritis self-help, chronic disease self-help, or fibromyalgia self-help course. In turn, annually provide the program(s) for individuals with arthritis and/or other chronic conditions as part of your job expectations or as a community volunteer;
- Hosting a forum and/or workshop in your community on arthritis, lupus, osteoporosis, weight management, physical activity, or nutrition;
- Advocating for environmental changes in your community, such as walking trails, healthy food choices in the break room or dining hall, lunch-n-learns, public forums, and ergonomically correct working facilities;
- Providing low cost home modifications for people with arthritis or osteoporosis to improve home safety and to help them remain independent;
- Providing and promoting marked, safe greenways (walking trails and/or paths that are wide enough to incorporate walkers, cyclists, etc.) around your business and/or your community. Local governments have the opportunity to consider requiring greenways and sidewalks when designing and/or expanding communities, subdivisions, housing units, and industrial parks;
- Incorporating physical activity, nutrition education and their affect on bone health, joint health, and cardiovascular health into existing school programs. This may include calculating calcium intake for a period of time as part of a math assignment, the amount of energy expended during different activities as part of a science experiment, joint protection techniques as part of a physical education or health course;
- Providing the use of a church classroom as a meeting place for a course, public forum, or support group.



PART III: Current Programs



Examples of how partners can integrate arthritis messages into existing programs includes:

- Including articles about arthritis, osteoporosis, lupus, and juvenile arthritis in your program or organizational newsletters;
- Providing lunch-n-learns for employees;
- Providing PACE or self-management courses as part of an employee wellness program;
- Referring clients who are concerned about aging issues, arthritis, or osteoporosis, to local and/or state resources.



Strong Heart

“I’m the parent of a child with arthritis. I deal with it all day, every day.”

-Christy Clark, Booneville

When her six-year old daughter said she wanted to play T-ball, Christy Clark, of Booneville, MO, hesitated. She later picked up the telephone and called Kaitlyn’s doctor. Christy Clark is not an overprotective mother – rather, she is the parent of a child with juvenile arthritis.



“Kaitlyn has gone through lab tests every eight weeks to check her blood,” said Christy. “She visits her pediatric rheumatologist and her eye doctor every four to six months. It’s been difficult.”

Kaitlyn’s mother knows all too well that her daughter is especially vulnerable to eye damage, that her knees and ankles frequently ache with stiffness and swelling . . . that the disease can affect internal organs and lead to permanent joint damage. “I’m the parent of a child with arthritis. I deal with it every day,” said Christy.

Juvenile arthritis affects nearly 4,000 Missouri children. Nationally, the disease affects more than 285,000 kids.

But unlike many patients across the nation, Christy is fortunate to have the help of a juvenile arthritis program. Missouri is one of the few states in the country that operates such a program – there are five juvenile arthritis care coordinators across the state. Each coordinator assists Missouri parents deal with various issues of juvenile arthritis. “[The central Missouri juvenile arthritis coordinator] has been wonderful,” says Christy.



Today, Kaitlyn appears to be going into remission, but Christy knows this could be temporary. Sometimes juvenile arthritis continues into adulthood and sometimes it stops getting worse or gets better as the child grows past adolescence. But for now, Kaitlyn’s mother just takes things one day at a time.

PART IV: Call To Action

Join Us in implementing this action plan.

In this plan lies a strategic framework that outlines some of the major long-term goals to be achieved in the next 10 years and measurable, intermediate outcomes to be achieved over the next 3-5 years.



Key partners will guide the efforts of the Missouri Arthritis Alliance in the development, implementation, and evaluation of this plan's goals, outcomes, aims, and activities. A draft and template for an operational plan is included as part of this publication (See Appendix 4). The target population, evaluation, partnerships, and time period are also part of the operational plan.

This Call to Action is aimed at:

- People with arthritis;
- Health care providers including rheumatologists, physicians, nurse practitioners, physical and occupational therapists, and health educators;
- Health care organizations including hospitals, health plans, local public agencies, and nursing home facilities;
- Human service agencies, such as senior centers, independent living centers, adult day care centers, and vocational rehabilitation centers;
- Policy makers and employers;
- Partners and advisory boards with emphasis on health and aging; and
- Individuals who want to help others.

Join the effort! Complete the operational plan template and submit a copy to the Missouri Arthritis and Osteoporosis Program (See Appendix 4). With collaboration, coordination, and an increase in the availability of programs, services, and quality of care throughout Missouri, arthritis efforts will be strengthened to ensure the best possible health outcomes for Missourians with arthritis and related conditions. By providing direction and combining resources, the overall goal of improving the quality of life among all Missourians will be achieved.

The following paragraphs contain information to assist you.

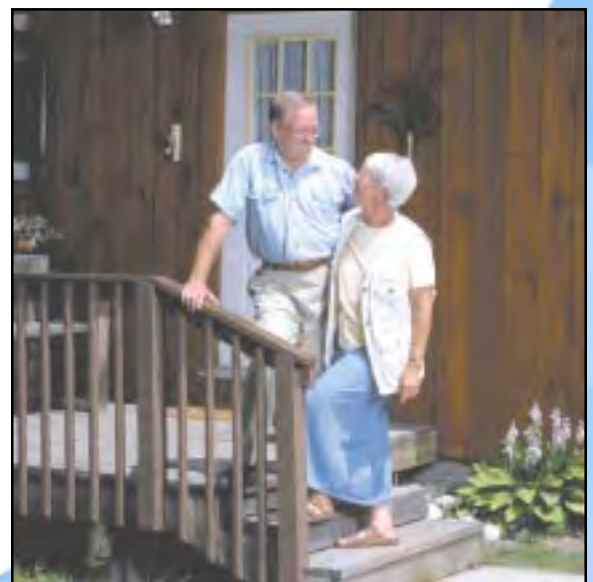
Disease Prevention & Management – Control of arthritis and related conditions can be categorized into three components: primary, secondary and tertiary prevention. Each component addresses the issue at different stages of the disease spectrum.

Primary Prevention: to prevent the occurrence of disease;

Secondary Prevention: to decrease the duration and severity of the disease through early detection and treatment before signs and symptoms occur;

Tertiary Prevention: to reduce complications and disabilities that can result from the existing disease.

Target Populations – This plan addresses the needs of Missourians by focusing on three primary target populations: people with arthritis and their families, the general public, and health care system. By focusing efforts on these groups, the development of a comprehensive action plan can be used to improve the health of Missourians with arthritis.





People With Arthritis and Their Families: Once individuals have been diagnosed with arthritis or have developed chronic joint symptoms, measures must be taken to manage their disease. Provision of services and programs that range from self-help courses (self-management) or exercise programs, to support groups for people with arthritis and their families are essential in improving physical and mental quality of life. Tailoring programs for specific populations is necessary to fully reach all those affected.

The General Public: Increasing awareness of the severity and disability associated with arthritis and related conditions will help promote early diagnosis and appropriate management and prevention or reduction of severe disability and pain.

Health Care Systems: Health care systems (physicians, physical therapists, nurses, HMO's, and employers) are frequently unaware of programs and services available throughout the state. Health care professionals are the most credible source of health-related information. Advice and referral from a health care professional is a powerful tool. Therefore, increasing awareness among health care professionals and providers of the appropriate clinical guidelines and standards of care, the importance of early diagnosis in minimizing the extent of disability and the services available for people with arthritis, health care providers can be better equipped to impact the quality of life of people with arthritis.

People With Arthritis Can Exercise!

Being in a group setting, with the encouragement of an instructor, makes all the difference for many patients with arthritis.

Every time Suzanne Pfeffer stops taking her PACE (People with Arthritis Can Exercise)/Rebuild class for a week or two, an exercise class designed by the Arthritis Foundation, stiffness creeps back to her legs.

Pfeffer, 71, has osteoarthritis in her right knee, and has been taking a PACE/Rebuild class for about three years. She attends the classes one hour a day, three days a week. “It has definitely helped me,” she said. “I get some relief from the stiffness that I have.” Exercises in the class are designed to improve flexibility, strength, endurance and balance.



Pfeffer likes to travel, and she has been to Spain and the Canary Islands. But when she travels, Pfeffer finds that she does not exercise on her own. That means the stiffness of osteoarthritis returns.

“I need a group, the group setting, doing it with other people who have the same problems and the encouragement of the instructor,” said Pfeffer.

Osteoarthritis is the most common form of arthritis, and it affects nearly 21 million Americans. Symptoms include pain and stiffness in the joints, most often in the knees.

PART V: Action Plan

Taking Stock In Missouri's Health

Mission

- Improve the quality of life among Missourians with arthritis and related conditions.

Rationale: Quality of life encompasses an overall sense of well being, including aspects of happiness and satisfaction with life as a whole. Health-related quality of life encompasses those aspects of overall quality of life that can be shown to impact either physical or mental health. On an individual level, this includes physical and mental health perceptions and their correlates, including health risks and conditions, functional status, social support, and socioeconomic status. On a community level, it includes resources, conditions, policies, and practices that influence a population's health perceptions and functional status.

The goals set forth in this plan provide general direction to Missouri's Arthritis Alliance.

Goals

- Reduce the disability caused by arthritis or joint symptoms. Disability is defined as a limiting health condition that interferes with the performance of socially defined activities and roles such as work;¹⁶
- Increase public awareness of arthritis and related conditions as the leading cause of disability, the mechanisms of prevention and management, and the resources available throughout the state;
- Increase expansion and continuation of arthritis education, programs, and support services in Missouri for people with arthritis and their families; particularly the elderly, women and children, underserved populations who may lack access to healthcare services; and other high-risk populations;
- Improve the quality of health care practices and enable accountable health care systems for all Missourians with arthritis and related conditions;

- Enhance and strengthen surveillance/monitoring of disease prevalence, related risk factors, and Healthy People 2010;
- Sustain and strengthen support of partners and policy-makers to address issues and policies for the advancement of this plan’s vision.

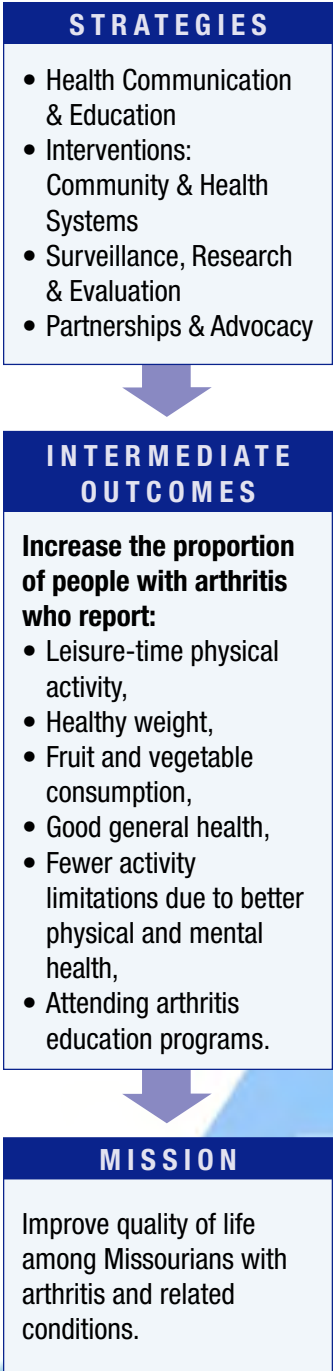
Success Indicators

The mission has guided the development of strategies and intermediate outcomes for people with arthritis. In order to achieve the identified goals and outcomes presented in this plan, specific aims need to be addressed through the application of several strategies: health communication and education; interventions in the community and health systems; surveillance, research and evaluation; and partnerships and advocacy. Figure 2 illustrates that through implementation of strategies, intermediate outcomes can be achieved. Through the achievement of intermediate outcomes over a period of time, the mission can be reached. The Following is an overview of the strategies, associated aims, and some suggested activities that are important in order to achieve the aims. Process, impact and outcome evaluation of activities, aims, and outcomes will be achieved through surveillance systems such as BRFSS, special surveys, RAC electronic database, and a number of other measurement tools. For measuring plan progress over the next five years, intermediate measurable outcomes are necessary to assess the success of Missouri’s efforts in the fight against arthritis.

Evaluation

To guide efforts and provide valuable information regarding the effectiveness of activities, a comprehensive approach must be taken to evaluate the outcomes, aims, activities and strategies carried out in this plan. Mechanisms for ongoing evaluation include process, impact, and outcome measures. Process evaluation, or formative evaluation, consists of measuring the immediate outputs related to the implementation of activities (for example, the number of participants). Impact evaluation, or summative evaluation, measures intermediate objectives (3-5 years), (for example, changes in knowledge, attitudes, beliefs and behaviors of participants). Outcome evaluation measures the long-term (5-10 year) effects on health status, morbidity, mortality, disability, and quality of life. Strategies can be evaluated through the use of a program activity database, standardized program evaluations, special surveys or use of an existing surveillance system such as the Behavioral

Figure 2





Risk Factor Surveillance System (BRFSS). Sharing of aggregate information between individuals and organizations that collect data on the same target populations is also essential to monitoring success. A description of the three components of evaluation follows.

Process Evaluation: Process evaluation is accomplished through regular monitoring and reporting of activities. For example, an electronic database will be utilized by the RACs to maintain a record of participants, programs offered and utilized, and other program-related questions for the MAOP.

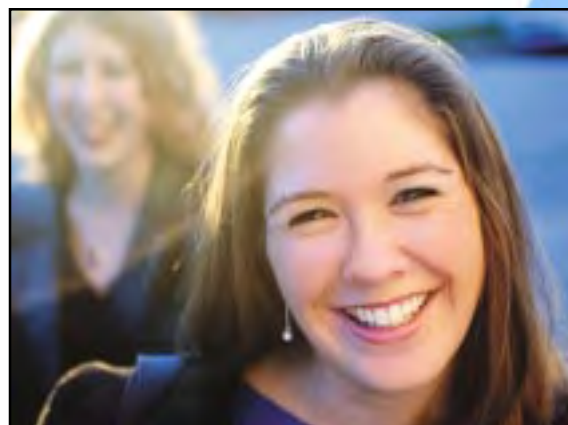
Impact Evaluation: Impact evaluation measures changes in knowledge and behaviors over 3-5 years. Surveillance using Missouri's BRFSS data will aid in measuring changes in behaviors, such as physical activity and weight status. Special surveys may need to be developed to measure changes in the public's perceptions of arthritis, education about prevention and management of arthritis, and utilization of the programs and services;

Outcome Evaluation: Outcome evaluation assesses the impact of activities over the long-term (5-10 years). Measuring changes in activity limitations and other quality of life indicators will be the greatest measure of success. BRFSS data will provide the necessary surveillance information to accomplish this type of evaluation. Other sources of information on hospitalizations and surgeries will be an important source for measuring changes in the economic burden of arthritis.

Intermediate Outcome/Measures:

- Proportion of the population with arthritis who have engaged in any physical activity, other than work;
- Proportion of the population with arthritis who report being obese;
- Proportion of the population with arthritis who report consuming the recommended five or more servings of fruits and vegetables a day;
- Proportion of the population with arthritis who report their general health status as fair or poor;
- Proportion of the population with arthritis who report activity limitations due to poor physical or mental health problems;
- Proportion of organizations (i.e., health departments, hospitals, and healthcare organizations) providing community disease prevention and health promotion education and activities;
- Proportion of the population with arthritis who have ever taken an arthritis education or disease management program;
- Proportion of the population of health professionals attending effective arthritis education programs.

In order to achieve the intermediate outcomes, twelve aims have been identified for Missouri and are addressed through the strategies of communication, intervention, surveillance/evaluation, and partnerships/advocacy strategies. For your convenience in planning and evaluating activities that you conduct, use the operational plan template (See Appendix 4).



Strategy 1

(Aims 1-3)

Communication/Education

A well balanced diet that includes the daily recommended servings of fruits, vegetables and grain plus regular physical activity are important elements in achieving and maintaining a healthy body weight.

Appropriate communication is the cornerstone for all our efforts, whether it is in developing partnerships, educating the public on arthritis, administering management tools, or influencing legislators. Identifying the appropriate media for varying audiences makes communication efforts cost-effective. Development of communication strategies tailored to target audiences will aim at increasing awareness of arthritis, its impact, management, and available services and resources, among the general public and especially among high risk populations.

Communication is necessary to raise awareness. We must develop collective strategies with consistent messages to reach entire populations. Many people with arthritis believe there is little they can do to affect their disease. Many affected by arthritis lack knowledge about their disease and effective means to prevent further disability. They need to know about programs and resources available and how to access these services. Public awareness and education are necessary to dispel widespread misunderstanding about arthritis and to link people to credible, accurate and useful information.

Health care providers are a crucial link in communicating with people with arthritis and their families. In order to support high quality care and maximize the effectiveness of those health care interactions, we need to enhance the availability of accurate arthritis-related information and skill development for health care providers. Health care providers need communication tools that will support their efforts to provide quality care.

AIM 1

By 2005, develop and implement a comprehensive marketing plan to increase awareness of arthritis; its seriousness, cost, prevention, benefits of early diagnosis; and to heighten the emphasis of its effect on quality of life.

Suggested Activities

- Develop tailored messages and identify and use appropriate media to meet the needs and concerns of target audiences;
- Educate policy makers on arthritis as a tremendous public health problem and the leading cause of disability;
- Educate the general public, health care professionals, health insurance providers, employers, and other relevant organizations on the treatment, self-management, economic burden, the severity of the disease, and its impact on disability and quality of life;
- Promote professional education courses;
- Promote early diagnosis by encouraging those who experience chronic joint symptoms to seek medical advice;
- Integrate arthritis messages within existing DHSS' divisions, bureaus and programs (Cardiovascular disease diabetes, women's health, minority health, aging, WIC, etc);
- Integrate arthritis messages within other state programs;
- Communicate to the general public, health care professionals, health insurance providers, employers, and other relevant organizations, the benefits of physical activity and weight management in terms of primary, secondary, and tertiary prevention;
- Participate in the National Press Conference focused on arthritis;
- Provide arthritis and osteoporosis information through Brown Bag Lunch programs, company display boards, and company/industry newsletters;
- Disseminate arthritis related data and research findings;
- Educate coaches, athletic directors, and athletic trainers about injury prevention and the importance of strengthening/conditioning techniques to reduce the risk of immediate injury and the long-term effects – osteoarthritis;
- Integrate osteoporosis prevention messages into existing curriculum in elementary, secondary, and higher education programs. Examples of such messages include appropriate calcium intake information, information on the reduction in soda consumption, tobacco use cessation, the importance of appropriate physical activity, and the importance of a balanced diet.

AIM 2

By 2005, increase the number of individuals with arthritis attending effective arthritis education and disease management programs.

Suggested Activities

- Increase statewide awareness of resources available for persons with arthritis and their families;
- Promote self-management programs offered by Regional Arthritis Centers, Arthritis Foundation Chapters, Local Public Health Agencies, and other organizations;
- Increase knowledge among health care professionals on the importance of self-management and referral to available programs;
- Promote effective disease management behaviors and practices among people with arthritis and related conditions;
- Empower people with arthritis with knowledge about their disease;
- Communicate the benefits of physical activity, weight management and other healthy behaviors for minimization of arthritis pain and disability among people with arthritis and health care professionals;
- Implement CDC tailored messages for people with arthritis;
- Integrate arthritis messages into other programs that reach the same target audiences;
- Become a provider of physical activity programs, self-management courses, and/or support groups for people with arthritis;
- Provide facility space for on-going physical activity programs, self-management courses, and/or support groups at reduced or no charge rate;
- Incorporate messages about physical activity and a balanced diet into presentations;
- Integrate weight management/osteoarthritis messages into existing weight management programs.

AIM 3

By 2005, develop and implement a system to improve access to and distribution of information for all Missourians.

Suggested Activities

- Create a systematic and efficient dissemination plan for information;
- Utilize current technologies to provide arthritis and osteoporosis educational programs through video/satellite conferencing;
- Establish a media database to efficiently and effectively distribute and track arthritis-related messages;
- Develop and maintain an arthritis website and link to other valid websites;
- Generate and disseminate press releases, research articles, and other documents to create awareness of arthritis, programs available and advancing research in the field of rheumatology, exercise, health related quality of life, aging and nutrition;
- Develop a system to share existing presentations among partners.



Strategy 2 (Aims 4-6)

Community & Health-Systems Based Programs



With most types of arthritis, regular physical activity and maintaining an appropriate body weight can be helpful in keeping arthritis-related discomfort to a minimum, while maximizing physical ability.

Identifying and targeting populations at greatest risk is a priority. The actual implementation of specific, effective interventions that led to a continuum of health services that includes primary, secondary and tertiary prevention, and supportive policies and environments conducive to prevention and improved quality of life are necessary to ensure sustainable programs. Interventions geared at the community and health systems need to incorporate strategies for primary (for example, reduction of risk factors), secondary (for example, early diagnosis), and tertiary (for example, self-management) prevention. Programs to facilitate change in knowledge, attitudes, and beliefs and behaviors that promote health and alleviate arthritis-related problems can ensure quality health care and services to people with arthritis. Activities must be tailored to reach different audiences, such as minorities, low income/low education level households, health care providers, seniors, athletes, or children.

Development and implementation of effective community-based programs will positively affect the physical, mental, social, and economic impacts on people with arthritis and their families. Implementation of health systems-based interventions can ensure quality health care and services to people with arthritis.

AIM 4

By 2005, increase the proportion of partners providing community programs and services to enhance and strengthen existing services and programs.

Suggested Activities

- Develop and/or adopt more evidence-based programs;
- Incorporate the inclusion of educational programs to reduce injury occurrence and the relationship between injury and arthritis;
- Incorporate into health/physical education courses, the inclusion of joint protection, body mechanics, arthritis risk factors, nutrition, and osteoporosis into the curriculum as standard practice;
- Conduct interventions at the worksite and school settings on protection from occupational and sports-related joint trauma and repetitive joint usage;
- Tailor interventions to target juvenile arthritis patients, women, elderly, minorities, the underserved (rural, innercity), and farmers;
- Train arthritis partners in advancing skills to provide state-of-the-art information and services;
- Recruit and retain more trainers and leaders to administer self-management programs;
- Become a provider of physical activity, self-management, and support group programs designed for people with arthritis and related conditions;
- Serve as a volunteer/counselor at activities designed for children with arthritis i.e., camps, aquatic programs, and walks.



AIM 5

Assist people with arthritis in remaining engaged in routine acts of daily living, school, employment, and social activities.



Suggested Activities

- Assist facilities in adapting accommodations and resources to aid people with arthritis in daily living activities;
- Promote adaptive tools and arthritis resources to people with arthritis to assist them in daily living activities;
- Provide educational programs to assist people with arthritis in optimally utilizing the available tools;
- Implement worksite wellness programs, like increased physical activity, nutrition forums, healthy lunch choices, weight management courses, smoking cessation programs, and self-management programs;
- Promote and advocate for ergonomically safe worksites;
- Provide education and appropriate modification for individuals with arthritis so they can remain employed;
- Identify high risk occupations and develop messages and modification recommendations to reduce occupational injury and repetitive motion trauma from such jobs;
- Encourage referral to appropriate services for people with arthritis, like vocational rehabilitation, Americans with Disabilities, occupational/physical therapy, and employee assistance programs;
- Provide transportation to/from physical activity, self-management, and support groups at minimal or at no cost;
- Promote accessible parks and trails;
- Develop, maintain, promote, and/or provide programs to minimize pain and disability associated with chronic conditions.

AIM 6

Improve knowledge, beliefs, and practices of health care professionals.

Suggested Activities

- Include arthritis education in allied health education programs, medical schools, and residency programs;
- Provide up-to-date arthritis information to health organizations and medical institutions;
- Assist organizations in implementing education and disease management programs within their institutions;
- Provide training opportunities and/or professional development programs for health professionals;
- Partner with organizations specializing in medical education;
- Advocate for core rheumatology training in all primary care physician training;
- Develop training modules for early diagnosis, self-management, physical activity, early rehab services, and mental health;
- Publish tailored arthritis education articles in medical societies and professional organization newsletters/publications;
- Distribute *Primer on Arthritis* and standards of care for best practices for people with arthritis to healthcare professionals;
- Provide and promote internships/community fieldwork for health professionals to include arthritis self-management programs;
- Refer patients/clients to physical activity and/or self-management programs designed for people with arthritis and chronic diseases.

Strategy 3 (Aims 7-9)

Surveillance, Research & Evaluation



Surveillance: Defining the burden of arthritis is an important step in efforts to target high-risk populations and to guide the development of interventions that lessen the impact arthritis places physically, economically, and emotionally on the person with arthritis and their families. Surveillance efforts need to be enhanced and gaps in surveillance need to be assessed. Assessment of all existing data that are available for defining the burden of arthritis must be identified. Further improvements in surveillance and research are imperative in guiding efforts and monitoring progress over time.

Research: Epidemiological, medical and pharmacological research will greatly advance efforts to improve the quality of life among Missourians. Examination of data will enhance our understanding of arthritis and the factors that play a role, the populations most affected, and the barriers faced. This data should be applied to planning and development of health promotion programs/ interventions. Research on disease management programs provides us with effective evidence-based interventions. Dissemination of program and population-based data will be invaluable to members of Missouri's Arthritis Alliance.

Evaluation: Integration of adequate evaluation measures to the action plan's activities will help determine the effectiveness of efforts and detect improvements in outcomes. Providing a strong evaluative foundation is beneficial in future program planning.

AIM 7

By 2005, develop, coordinate and implement a plan for on-going data collection, analysis and distribution of information.

Suggested Activities

- Explore new avenues/opportunities for data acquisition;
- Monitor activities of RAC participants, programs and services through an electronic database;
- Determine methods for juvenile arthritis and lupus surveillance;
- Support the inclusion of additional BRFSS questions/modules to better understand the burden of arthritis-related factors in Missouri;
- Conduct analysis of BRFSS data annually/bi-annually to develop/update burden reports or fact sheets;
- Monitor progress of Healthy People 2010 objectives related to arthritis;
- Publish summaries of Healthy People 2010 arthritis objectives;
- Disseminate current arthritis research findings;
- Support, coordinate, develop, administer, and/or conduct analysis of special surveys related to arthritis issues.



AIM 8

Conduct epidemiological research to improve our understanding of factors related to arthritis, barriers to services and related health care issues.

Suggested Activities

- Support and promote research to better understand treatment and management of arthritis; risk factors; cost analysis – physical, emotional, and economic; disability; and quality of life;
- Publish reports and other documents for public health organizations and health professionals to increase knowledge and understanding of arthritis and related factors;
- Develop and implement a prioritization model based on morbidity/quality of life/healthy life years for chronic diseases to show the impact arthritis has in relation to other chronic diseases;
- Collaborate with academic institutions to develop epidemiological studies to evaluate arthritis self-management programs/materials.

AIM 9

Develop and coordinate a plan for evaluating process, impact and outcome measures of arthritis and osteoporosis program activities.

Suggested Activities

- Integrate process, impact and outcome evaluation measures into all relevant activities;
- Develop a systematic plan for evaluating future activities;
- Develop annual reports with a compilation of evaluated activities;
- Evaluate existing disease management programs to assess effectiveness;
- Publish reports directed at specific audiences to relay findings;
- Develop a data collection system for monitoring arthritis and osteoporosis program activities.

Strategy 4

(Aims 10-12)

Partnerships & Advocacy

Partnerships: Partnerships are an essential component in achieving the goals set out in this action plan. Only through coordinating efforts with the MAOP, Arthritis Foundation Chapters, MARRTC, and the other members of the Missouri Arthritis Alliance, can Missouri implement and sustain a broad range of activities. The Alliance, through this plan, will enhance, strengthen, and sustain links that address issues that are complimentary with the efforts of DHSS to improve the quality of life for people with arthritis: physical activity, early diagnosis and treatment, and self-management. Establishing partners at the state and local levels will enable Missouri to be comprehensive in its approach to planning and implementing activities. It is also important that partners in the fight against arthritis assist in the dissemination of this action plan and in the recruitment of partners who are willing to incorporate activities into their organizational structure and/or daily activities.

Advocacy: Changes in knowledge and behavior can substantially impact a person's health. However, improvements in access to care and medications, increased research and funding, and implementation of policies to promote equity can have a far-reaching impact on quality of life for people with arthritis.

AIM 10

Create, strengthen and enhance partnerships with organizations, businesses, and community organizations (community partners) to develop, coordinate, and maximize resources.

Suggested Activities

- Comprehensively address the issues of primary, secondary, and tertiary prevention that affect the quality of life of Missourians with arthritis or chronic joint symptoms with community partners (schools and worksites);
- Identify and develop partnerships to strengthen and expand existing arthritis efforts;
- Build collaborations/partnerships with existing DHSS programs, agencies, and organizations that address the needs of minority populations, women, children, and aging populations;
- Develop and maintain a coordinated, statewide grassroots volunteer network;
- Develop a communication committee and listserv to keep all partners aware of messages that are being distributed and activities held that are geared towards specific populations to prevent duplication of efforts;
- Develop a work plan (in-depth evaluation) of all efforts in terms of resources and responsibility allocations;
- Link website to reputable arthritis sites such as the MAOP, MARRTC, and AF sites to assist individuals seeking arthritis information obtain current, accurate and reliable information.

AIM 11

Enhance funding for arthritis and related diseases in terms of research, treatment and interventions to reduce disability and pain.

Suggested Activities

- Coordinate strategies and activities to maximize/optimize resources in communicating messages and providing programs and services;
- Keep abreast of funding opportunities/resources and disseminate the information in a timely manner;
- Inform partners of available funding opportunities and assist them in acquiring funding in the areas of research, treatment and interventions;
- Become informed about available research and programs/interventions offered (more evidence-based; information on research that can have an impact on how we practice) and disseminate the information in a timely manner;
- Assist partners to acquire adequate funding to support arthritis and osteoporosis initiatives.

AIM 12

Advocate for more emphasis on arthritis and related disability as a priority issue, especially for the increasing aging population.

Suggested Activities

- Advocate for medical reimbursements for PT/OT, surgery, medication, and orthodontics (use economic burden data to advocate change in HMO reimbursements);
- Keep abreast of policies (insurance, legislative, etc.) that may/will affect the lives of people with arthritis;
- Advocate for physical activity, quality of life and arthritis modules to be asked in the same BRFSS year to observe trends over time;
- Promote physical activity and self-management programs for people with arthritis through insurance provider newsletters;
- Support the development of a chronic disease prioritization model focused on morbidity, quality of life and healthy life years vs. mortality;
- Advocate for cost coverage of arthritis self-management, physical activity, and educational programs;
- Advocate for an adequate number of specialists who treat people with arthritis, i.e., rheumatologists, physical therapists, etc.;
- Advocate for the referral of people with arthritis to appropriate specialty care;
- Sponsor events and activities focused on children with arthritis, like camps, aquatic programs, and walks.



Gardening with Arthritis

Robert Green, age 69, knows that remaining active is important to managing his arthritis, and he does not let the disease stop him from enjoying the outdoors. In fact, you can frequently find Green playing in the dirt as he tends to his backyard garden. “I’m retired, and I needed something to help me pass the time,” he said. “I really enjoy how gardening keeps me active and I love the wonderful flavors you get from home grown foods.” Green, of Centralia, MO, made some minor adjustments in form and style and found gardening an ideal way to be outside and keep moving.

Most of the changes Green made were easy, like choosing the tools that allow him to garden with gusto without hurting himself. “I use a tiller that is much smaller than the regular sized ones,” said Green. “It was inexpensive and I can operate it easily and not put too much stress on my joints. You just learn to adapt to your situation.” Green also uses a special, low-to-the-ground stool that keeps him close to his garden floor. This helps to keep stress off of his knees, where he experiences most of his arthritis pain. Cushioned kneepads put the finishing touch on his routine, as sometimes he needs to kneel.

“Look at what you can do, not what you can’t do.”

— Karen Funkenbusch,
Missouri AgrAbility
Project

Moderate physical activity, like gardening, is an important part of arthritis self-management. Starting a regular physical activity program makes everyday activities like carrying groceries and getting in and out of the tub or car easier; it also gives those with arthritis a chance to think about other things.

“Gardening gets my mind off of the pain. It’s always in the background, sure, but it is out of your mind,” Green said. “Plus, it cuts down on the grocery bills!”



Missouri’s arthritis community works hard to educate Missourians with arthritis about the benefits of moderate physical activity. Through proper self-management, patients can realize their dreams without the constraints of arthritis and begin to take control of their disease.

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Healthy People 2010 Objectives

Healthy People 2010 objectives marked by an asterisk (*) will be monitored and used as an evaluation mechanism to ensure proposed outcomes are being achieved.

- 2-1 (Developmental) Increase the mean number of days without severe pain among adults who have chronic joint symptoms.
- 2-2 Reduce the proportion of adults with chronic joint symptoms who experience a limitation in activity due to arthritis.*
- 2-3 Reduce the proportion of all adults with chronic joint symptoms who have difficulty in performing two or more personal care activities, thereby preserving independence.*
- 2-4 (Developmental) Increase the proportion of adults aged 18 years and older with arthritis who seek help in coping if they experience personal and emotional problems.
- 2-5 Increase the employment rate among adults with arthritis in the working-aged population.
- 2-6 (Developmental) Eliminate racial disparities in the rate of total knee replacements.
- 2-7 (Developmental) Increase the proportion of adults who have seen a health care provider for their chronic joint symptoms.
- 2-8 (Developmental) Increase the proportion of persons with arthritis who have had effective, evidence-based arthritis education as an integral part of the management of their condition.
- 2-9 Increase the proportion of local health departments that have established culturally appropriate and linguistically competent community health promotion and disease prevention programs.*
- 2-10 Increase the proportion of adults who are at a healthy weight.*
- 2-11 Reduce the proportion of adults who are obese.*
- 2-12 Reduce the proportion of adults who engage in no leisure-time physical activity.*
- 2-13 Increase the proportion of adults who engage regularly, preferably daily, in moderate physical activity for at least 30 minutes per day.*
- 7-11 Increase the proportion of adults who engage in vigorous physical activity that promotes the development and maintenance of cardio-respiratory fitness three (3) or more days per week for 20 or more minutes per occasion.*
- 19-1 Increase the proportion of adults who perform physical activities that enhance and maintain muscular strength and endurance.*
- 19-2 Increase the proportion of adults who perform physical activities that enhance and maintain flexibility.*

Missouri Arthritis Alliance

This is a list of the initial partners representing professional organizations, academia, business, general public, and government (individuals/organizations) working to improve the lives of people with arthritis. If your name and/or institution have been left off inadvertently, please call the 800 number immediately. Also, if you or your organization is interested in becoming involved in the Missouri Arthritis Action Plan, please join the Missouri Arthritis Alliance by calling 800-36-0935 or completing and mailing the form in Appendix 1 on page 51.

Area Health Education Center-Northeast Missouri Arthritis Foundation

Eastern Missouri Chapter

Central Missouri Branch Office

Western Missouri Chapter

BJC Health System

Baptist Home, The

Bell City Methodist Church

Black River Coliseum

Boone Clinic

Cape Girardeau Senior Center

Cape Physician Associates

Carter County Nutrition Center, East

Caruthersville Community Center

Caruthersville Nursing Home

Center for Clayton, The

Center VFW Hall, City of

Center Town Hall, City of

Central Missouri State University

Chaffee Medical Clinic

Chaffee Nutrition Center

Charleston Manor

Chateau Girardeau

Club Woodrail

City of Independence Housing Authority

Clark County Nursing Home

Columbia Mayor's Council on Physical Activity

Delta Community Center

Ellington Senior Nutrition Site

Family Resource Center

First Baptist Church – Oak Ridge

Forget Me Not Senior Center

Governor's Council on Disability

Governor's Council on Fitness and Physical Activity

Gregg Community Center

Hammon's Heart Institute

Health Connection

HealthNet

HealthSouth

HealthSouth Rehab

Healthwise Center, St. Peters

Heritage Physical Therapy

Hoover Eldercare

Hospitals:

Audrain Medical Center

Barnes/Jewish St. Peters Hospital

Boone Hospital Center

Children's Mercy Hospital

Christian Hospital NE/NW, Graham Medical Center

Des Peres Hospital

Golden Valley Memorial Hospital

Hannibal Regional Hospital

Heartland Health System

Northeast Regional Medical Center

Saint Luke's Regional Hospital

St. Anthony's Medical Center

St. Francis Medical Center

Center for Health and Rehab

St. John's Mercy Hospital

St. John's Mercy Medical Center

St. Joseph Medical Center

St. Joseph's Hospital & Health Center

Kirkwood

St. Charles

St. Mary's Hospital Physical Therapy Department

Samaritan Hospital

Scotland County Memorial Hospital

Skaggs Hospital-Branson

Sullivan County Memorial Hospital

Hotels/Motels:

Super 8, Kennett

Charleston Inn

Days Inn: Kirksville, Sikeston

Smalley's Motel, Van Buren

Independent Living Center of Southeast Missouri Department of Health
and Senior Jewish Community Center Association,
Creve Coeur and Chesterfield

Services Kansas City Missouri Parks and Recreation Department

Kirksville College of Osteopathic Medicine

Internal Medicine/Geriatrics

Grants and Program Development

Community Development Elder Link

Kirksville Parks and Recreation Department

Kirksville Physicians & Surgeons

LIFE Independent Living

Local Public Health Agencies

Iron County Health Department

Jefferson County Health Department

Kansas City Missouri Department of Health

Knox County Health Department

Mercer County Health Department

New Madrid County Health Department

Putnam County Health Department

Stoddard County Health Center

Longview Community College

Lupus Foundation of America, Inc.

Missouri Chapter (St. Louis)

Kansas City Chapter

Lincoln University

Marble Hill Senior Center

Meadowbrook Residential – Ironton

Mid America Regional Council in Kansas City,

Missouri and Senior Centers

Missouri's Area Agencies on Aging

Missouri Centers for Independent Living
 Missouri Department of Health and Senior Services
 Division of Aging
 Division of Chronic Disease Prevention & Health Promotion
 Diabetes Control Program
 Breast Cervical Cancer Control Program
 Cardiovascular Health Program
 Health Promotion
 Office of Surveillance, Research, and Evaluation
 Office on Women's Health
 Office on Minority Health
 Office of Public Information
 Division of Maternal Child Family Health
 Bureau Special Health Care Needs
 Centers for Local Public Health
 Community Health Assessment Resource Team
 Missouri Hospital Association
 Missouri League of Nursing
 Missouri Medical Association
 Missouri Nurses Association
 Missouri Occupational Therapy Association
 Missouri Osteoporosis Foundation
 Missouri Patient Care Review Foundation
 Missouri Physical Therapy Association
 Missouri Public Health Association
 Missouri Silver Hair Legislature
 Missouri Society of Health Educators
 Missouri Vocational Rehabilitation
 Monett Senior Center
 Montgomery County Care Share Program
 National Chronic Fatigue Syndrome and Fibromyalgia Association
 Northeast Regional Health & Fitness Center
 Northeast Regional Medical Center
 Nutrition Center/Community Building – Portageville
 Older Women's League
 Orthopedic Associates-Cape Girardeau
 Palmyra Rural Housing
 Parish Nurses Association, Kansas City
 Parkland Therapy
 Perry Park Center
 Pharmaceutical
 Centocor
 Pharmacia/Searle
 Merck
 Wyeth-Ayerst/Immunex
 Pfizer
 Aventis
 Proctor and Gamble
 Searle
 MGI Pharma, Inc.
 Ortho-McNeil
 Purdue Pharm LP
 Eli Lilly
 Boehringer Ingelheim
 Amgen, Inc.
 Barr Laboratories
 Portageville Public Pool
 Queeny Park/Greensfelder Recreation Complex
 Rainbow Village Community Center
 Regional Arthritis Centers
 Central Missouri Regional Arthritis Center
 Eastern Missouri Regional Arthritis Center
 Greater Kansas City Regional Arthritis Center
 Northeast Missouri Regional Arthritis Center
 Northwest Missouri Regional Arthritis Center
 Southeast Missouri Regional Arthritis Center

Southwest Missouri Regional Arthritis Center
 ReStart
 Reynolds County Sheltered Workshop
 Riverside Regional Library
 Rural Advocates for Independent Living
 St. John's Regional Health System—Springfield/Joplin
 St. Louis University
 School of Public Health
 School of Medicine-Division Rheumatology
 Samuel U. Rodgers Health Care Center
 Scleroderma Support Group
 Sears Youth Center
 Senior Citizen's Housing Authority Center – Van Buren
 Shepherd Centers, Kansas City
 Sjogren's Syndrome Support Group
 SSM Health and Wellness
 Swope Parkway Health Care Center
 Truman Medical Center
 Truman State University
 Nursing Department
 Health and Exercise Science
 Twin Rivers Fitness Center
 Twin Towers – Popular Bluff
 United HealthCare
 Universal Health and Fitness – Cape Girardeau
 University of Missouri – Columbia Campus
 Missouri Arthritis Rehabilitation Research Training Center
 Family Health Center
 Health Information Center
 College of Agriculture, Food and Natural Resources
 University Extension
 School of Health Professions
 Health Connection
 ElderCare
 Department of Cardiopulmonary and Diagnostic Professions
 Department of Physical Therapy
 Department of Occupational Therapy
 Department of Psychology
 School of Medicine
 Department of Rheumatology
 Department of Physical Medicine and Rehabilitation
 Department of Family and Community Medicine
 School of Nursing
 University of Missouri – Kansas City Campus
 University of Missouri – St. Louis Campus
 University Outreach & Extension
 Washington University
 Division Rheumatology
 School of Medicine
 Wegener's Granulomatosis Association, International
 WellAware
 Wellbridge by SSM
 Westside Church of God, Popular Bluff
 Yarco Group
 YMCAs/YWCAs
 4 Rivers YMCA
 Carondelet Family YMCA
 Edward Jones Family YMCA
 Emerson Family YMCA
 Kirkwood Family YMCA
 Mid-County Family YMCA
 Monsanto Family YMCA
 Northwest County Family YMCA
 Sikeston YMCA
 South County Family YMCA
 Southside YMCA
 Webster Groves Family YMCA
 West County Family YMCA
 O'Fallon YMCA
 Joplin YMCA

Appendix 1

If you are interested in being a part of the Missouri Arthritis Alliance, please complete this form and mail, e-mail, or fax it to:

Missouri Arthritis Alliance
Missouri Arthritis & Osteoporosis Program
P. O. Box 570
Jefferson City, Missouri 65102-0570
Fax: 573-522-2898
Email: ankenm@dhss.state.mo.us

Name: _____ Credentials: _____

Title: _____

Agency: _____

Address: _____

Phone: _____ Fax: _____

Email: _____

Web: _____

I would like to:

☐ Serve as a member of the Missouri Arthritis Advisory Board

☐ Become a self-management course leader

☐ Become a physical activity course leader

☐ Serve as a member of a Speakers Bureau

☐ Provide a facility for course(s)

☐ Advocate for greenways/sidewalks/walking paths

☐ Learn more about opportunities/needs in my community

☐ Become a member of my local Arthritis Foundation Chapter

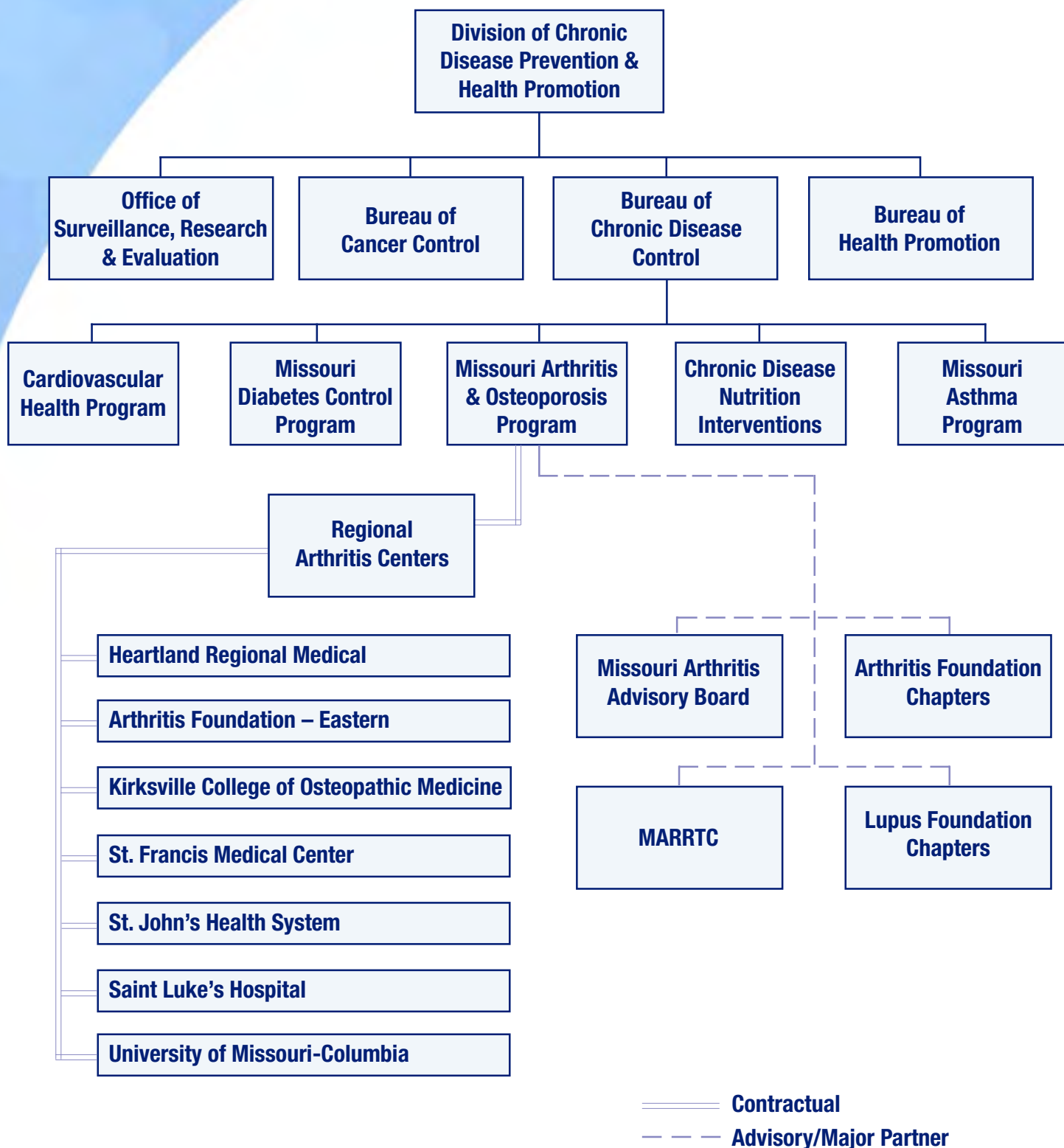
☐ Become a member of my Regional Arthritis Advisory Board

☐ Other: _____

☐ Other: _____

Appendix 2:

MAOP Organizational Chart 2002



Appendix 3

Missouri Regional Arthritis Centers

The MAOP has a statewide network of Regional Arthritis Centers (RACs) that provide information and support for persons and families affected by arthritis. This includes organizing community support groups, arthritis self-help courses, and land and aquatic exercise classes.

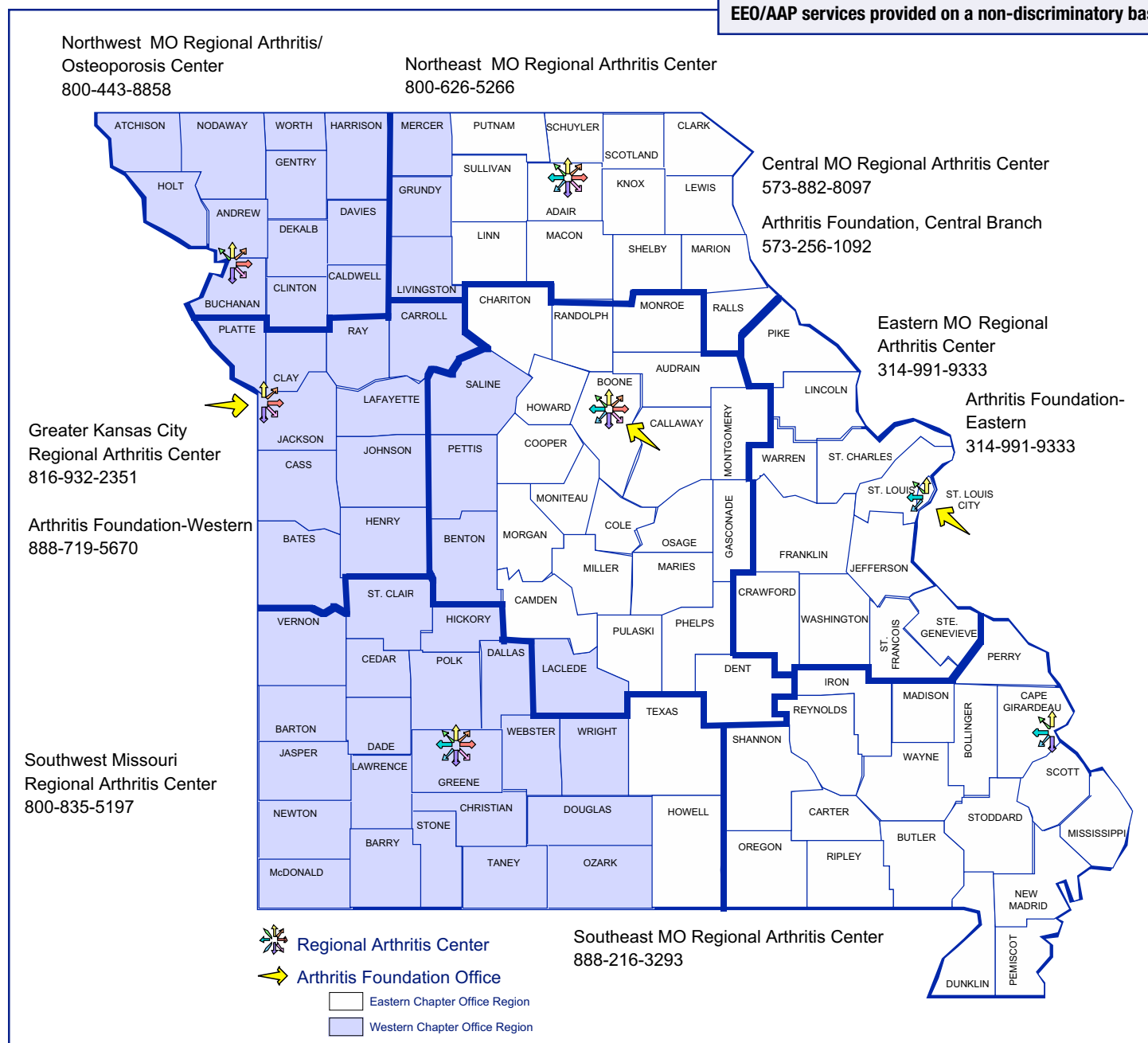
The RACs also organize continuing education courses for physicians, nurses, and allied health professionals and offer public forums and general presentations on state-of-the-art care for rheumatic diseases.

NEED MORE HELP?

Contact your local RAC.

Hearing-impaired citizens' telephone
1-800-735-2966.

EEO/AAP services provided on a non-discriminatory basis



Missouri's Fight Against Arthritis – Operational Plan

Lead Agency	Missouri Arthritis & Osteoporosis Program (MAOP)	Contact Person	Mary Ellen Ankeney
Web Site	www.dhss.state.mo.us	Address 1	Bureau of Chronic Disease Control
Partners	Missouri Arthritis Foundation Chapters	Address 2	P.O. Box 570
	MARRTC	City/State/Zip	Jefferson City, MO 65102-0570
	CDC	Phone	573-522-2879
		Fax	573-522-2898
		Cell/Mobile	NA
		Email	ankenm@dhss.state.mo.us

Strategy	Communication		
Aim			
Activity	CDC's Arthritis Awareness Campaign		
Target Population	General Public	Target Completion Date	December 2003

Task – Implement CDC Arthritis Campaign	Lead Person/Partner	Evaluation Measure	
Develop, Test, and Release Campaign to core states.	CDC		
Write contract with news network to air radio spots.	MAOP		
Coordinate with Arthritis Foundation Chapters	MAOP, AF Chapter Presidents		
Secure sponsors to air radio spots on more stations to saturate market with message	AF Presidents and staff		

Missouri's Fight Against Arthritis – Operational Plan

Lead Agency		Contact Person	
Web Site		Address 1	
Partners		Address 2	
		Phone	
		Fax	
		Cell/Mobile	
City/State/Zip		Email	

Strategy	
Aim	
Activity	
Target Population	Target Completion Date

Task – Implement CDC Arthritis Campaign	Lead Person/Partner	Evaluation Measure	Comments



Arthritis Action Plan: Missouri's Fight Against Arthritis

Please take a moment to provide feedback about this publication. The information you provide will assist with the development of future plans and initiatives.

Where did you obtain a copy of the plan?	<input type="checkbox"/> Mail	<input type="checkbox"/> Internet	<input type="checkbox"/> Other
Was this plan useful to you?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
Did this plan increase your knowledge of:			
Arthritis?	<input type="checkbox"/> Yes	<input type="checkbox"/> Partially	<input type="checkbox"/> No
Juvenile Arthritis?	<input type="checkbox"/> Yes	<input type="checkbox"/> Partially	<input type="checkbox"/> No
How you can help?	<input type="checkbox"/> Yes	<input type="checkbox"/> Partially	<input type="checkbox"/> No
Programs/Services available?	<input type="checkbox"/> Yes	<input type="checkbox"/> Partially	<input type="checkbox"/> No
I/we will be able to use this plan in my job/community	<input type="checkbox"/> Agree	<input type="checkbox"/> Disagree	<input type="checkbox"/> Unknown/Uncertain

If YES, what did you find particularly useful?

If **NO**, what would have made this plan useful?

Was the plan content practical and understandable? ☐ Yes ☐ No

If **NO**, what changes would you recommend?

What additional information would you have liked included?

Are you interested in receiving a copy of the *Missouri Arthritis Report 2001*?

- ☐ Yes, please send me a copy of the report.
☐ Yes, please send additional information as it becomes available.
☐ No, do not send any information at this time.

Name: _____

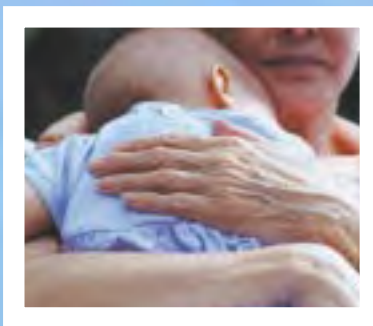
Title: _____

Agency: _____

Address: _____

Please return this survey to:

Missouri Arthritis & Osteoporosis Program
Missouri Department of Health & Senior Services
P.O. Box 570
Jefferson City, MO 65102-0570
Fax: 573-522-2898



Arthritis and Osteoporosis

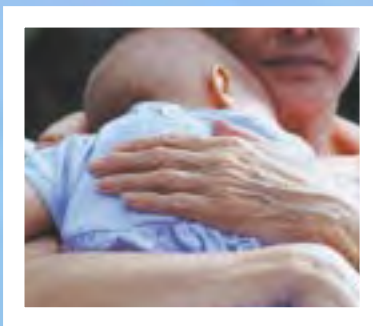
Missouri Department of Health & Senior Services
Bureau of Chronic Disease Control

This publication was supported by Grant/Cooperative Agreement Number 99038 from the Centers for Disease Control and Prevention (CDC). Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the CDC.

Alternate forms of this publication for persons with disabilities may be obtained by contacting the Missouri Department of Health and Senior Services, Division of Chronic Disease Prevention and Health Promotion, P.O. Box 570, Jefferson City, MO 65102-0570, 1-800-316-0935.
Hearing impaired citizens telephone 1-800-735-2966.

AN EQUAL OPPORTUNITY/AFFIRMATIVE ACTION EMPLOYER
Services provided on a non-discriminatory basis.





Arthritis and Osteoporosis

Missouri Department of Health & Senior Services
Bureau of Chronic Disease Control

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